



The Research Connection

The Psychosocial & Nursing Advisory Board to
the New Jersey Commission on Cancer Research

Editor: Kathleen Walsh Scura, Ed.D., RN

Number 1

The Joint Psychosocial & Nursing Advisory Group to the NJCCR was appointed to advise the Commission of special research needs pertaining to nursing, psychology, sociology, and related disciplines for the purpose of addressing gaps in vital areas of cancer research and cancer care in New Jersey.

2005 Psychosocial & Nursing Advisory Group Members

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Wellness Conference a Tremendous Success

by
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More than 60% of people diagnosed with cancer now survive five years or more after treatment. Despite significant advances in cancer treatment and increased attention to general health, little is known about the level of wellness experienced by these survivors. In fact, many survivors who anticipated a return to premorbid health find themselves experiencing ongoing and distressing health and psychosocial sequelae.

In response to this critical need, the Psychosocial/Nursing Advisory Group to the New Jersey Commission on Cancer Research sponsored a one day professional education conference titled "Fostering Wellness after Cancer."

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This conference held at Seton Hall University explored current research in survivors' wellness; the role of health care professionals in fostering and promoting quality of life for survivors; and the components of a compelling research agenda.

Goals of the conference were to: (1) Review current literature dealing with wellness among cancer survivors; (2) Promote psychosocial/nursing research in wellness and cancer survivorship; (3) Assist clinicians and academics to network to find mutually compatible interests and to promote collaboration in wellness and cancer survivorship research; (4) Promote evidence-based practice to promote wellness among cancer survivors; (5) Discuss the impact of cancer on sexuality among survivors; and (6) Assess the role of nutrition in promoting wellness among cancer survivors.

The audience included over 100 health care professionals including nurses, social workers, therapists, physicians, nursing and psychosocial researchers, allied health professionals, students, and health care administrators.

Julia Rowland, PhD, Director, Office of Cancer Survivorship, National Cancer Institute, National Institutes of Health presented the keynote address: Emerging Issues in Survivorship Research. Her inspirational talk set the stage for the entire day, and created a framework for considering the subsequent speakers and ideas. Generosa Grana, MD, Division Head, Hematology/Oncology, Cooper Hospital. University Medical Center discussed the latest in effective surveillance and monitoring, which provided the basis for participants to frame services and research questions relative to cancer survivorship. The psychosocial adjustment to wellness after treatment was presented by Jamie Ostroff, PhD, Chief Behavior Sciences Services, Memorial Sloan-Kettering Cancer Center. During lunch, Michael Gallo, PhD, Professor of Environmental and Occupational Medicine, Associate Director of the Cancer Institute of New Jersey candidly shared his personal and intimate feelings about his experience as a health professional/cancer survivor. Dr. Gallo then led a stimulating discussion with Drs. Rowland, Grana, Ostroff, Rabinowitz, and Ottery.

Attendees were both moved and inspired by Dr. Gallo's provocative insights. The afternoon session featured Barbara Rabinowitz, PhD, MSW, Director of Oncology Services, Meridian Health System who shared her expertise with a thought provoking talk on helping patients and families face the hard questions about sexuality. This often difficult topic, so critical to the development of services and the research agenda was presented in a clear and comprehensive manner. Helpful tips on promoting good nutritional strategies after cancer treatment was presented by Faith Ottery, MD, PhD, Director of Clinical Research, Savient Pharmaceuticals. Dr. Ottery's wealth of clear, targeted information about nutrition had considerable relevance for all who attended and provided an important foundation for the development of outreach to cancer survivors. The conference concluded with Denyse Adler, MA, President, The Adler Group, facilitating a wrap-up session on forging alliances and moving forward with research and education. Participants left excited and energized by the speakers. Conference evaluations were extremely positive. One participant remarked that this was one of the best conference ever attended on a much needed topic.

Psychosocial Interventions with Cancer Survivors

by

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Adjustment to "life after cancer" includes the adjustment to physical, emotional, cognitive, social, sexual and spiritual changes, many of which are unforeseen by individuals navigating the world of diagnosis and treatment. Late effects vary widely; some are determined by the specific cancer diagnosis and treatment, while others are more dependent upon demographic, personal, or social characteristics. Overriding these differences is the "Damocles Syndrome" (Koocher and O'Malley, 1981) the universal fear of recurrence, and the uncertainty of whether one is truly "cured."

In working with cancer survivors to facilitate adjustment to the "new normal", clinicians must be prepared to address the many domains

which the survivor faces. Primary among these is the management of ongoing health care, and the anxiety that may accompany this effort. Following cancer treatment, many patients find it difficult to prioritize their reactions to physical changes or discomfort. The competing wishes to feel safe, but to distance from the medical community, paired with uncertainty regarding what complaints require an oncologist and which should be redirected to a primary care physician paralyze many survivors during a period in which there is often a heightened awareness of physical symptoms. Many survivors need to be helped to find a physician with whom they are comfortable, and establish a regular follow-up schedule. Survivors can be guided to address their confusion and anxiety with their physicians, and to ask direct questions to allay concerns. These questions may include: for what symptoms do I *need* to contact you immediately? What changes should I be watching for specifically? If I have this (pain, sensitivity, stiffness, sensation) again—how long should I wait before contacting you? Is there a nurse or physician's assistant I can contact to help me assess my worries? What prevention or wellness strategies would be most helpful to me? For many survivors staying informed about their illness can be helpful; for others it can be overwhelming. Identifying personal coping strategies is important in facilitating adjustment to cancer; this may include knowing whether, and in what ways information is useful.

Cognitive-behavioral interventions are often helpful in coping with the uncertainty of cancer survivorship. Clinicians can help survivors to look for distorted cognitions, or dysfunctional ways of thinking. Thought records can be very helpful in this endeavor, with survivors recording disturbing health related thoughts, and using individual sessions to challenge distorted thinking, and reframe experiences. Common dysfunctional ways of thinking may include: all-or-nothing (black or white) thinking, a tendency to evaluate situations in extreme categories; catastrophizing, the inclination to magnify mistakes, faults, or weaknesses, while minimizing positive situations; over-generalizing, assuming that because something happened once, it will *always* occur this way; unrelenting standards, imposing an unrealistic set of "shoulds" upon yourself and others, establishing unrealistic

expectations which are unlikely to be met, thereby leading to feelings of failure and inadequacy. (Blackburn, 1987). As survivors learn to recognize these habitual ways of thinking, they can better combat distorted thoughts, and reduce emotional distress.

Group support can be instrumental in combating feelings of isolation among cancer survivors. As many people in their immediate circle of family and friends may be anticipating the "return" of the person they knew prior to diagnosis, the cancer survivor may find that the experience has changed them in unanticipated ways. The expectations of others, no matter how well meaning, may feel like a demand they can not meet. Sharing these concerns with others who are adjusting to life-after-cancer can provide validation, communication skills, and social support.

Stress management is a skill that survivors may find particularly useful. While stress can be managed in a number of effective ways, interventions to teach survivors to balance activities, recognize shifting priorities, and identify situations and individuals that produce stress are particularly important. Survivors may be helped to strike the optimum balance between healthy distraction, and unhealthy denial. Relaxation strategies including deep breathing, imagery, meditation, art, music and prayer can be extremely useful as well.

Physical exercise has been found to improve quality of life among cancer survivors (Courneya et.al. 2003), particularly in areas of physical functional well-being. Some long term physical side effects of cancer or its treatment may not respond to exercise alone. Decreased libido, impotence, or menopausal symptoms may require help from a sex-therapist. Similarly osteoporosis, heart disease, loss of fertility, edema, and chronic pain are conditions that may require specialized professional attention. Both medical and mental health clinicians should be prepared to help survivors access these resources.

As growing numbers of people are surviving cancer, it becomes increasingly important for professionals working with an oncology population to be well versed in the long term effects of cancer

and its treatment. While many specialized interventions are effective in treating late effects, continued research in this area is required to refine and improve our care of this growing population.

References for this article are available by contacting the NJCCR at 609-633-6552 or (njccr@doh.state.nj.us).

Psychosocial Long Term Effects of Surviving Teenage Cancer

by

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Extensive data on the long-term effects of cancer treatment continues to be gathered by researchers. Since the beginning cures of cancer were first witnessed in children with Acute Lymphocytic Leukemia, testicular cancer and Hodgkins Disease, the long-term effects of cancer have been recognized for a greater length of time among childhood survivors. Based on findings from early childhood survivors, pediatric cancer protocols were altered to achieve the goal of eradicating disease with the least amount of treatment so that the long-term effects of surviving cancer were minimized. Long-term effects are known or expected medical problems that can occur months to many years after cessation of cancer treatment and occur with some degree of frequency among individuals who have undergone certain treatments (Ganz, 1988). The long term effects of cancer treatment in children and adolescents can range from obvious to subtle, and can include impairment in activities of daily living, cognitive impairment, and other overt physiological sequela, or they may be subclinical and are only identified with screening and testing. Less obvious are the psychosocial sequelae of surviving teenage cancer.

Over the past twenty-five years, substantial emphasis has been placed on investigations of the psychosocial sequelae of surviving childhood and adolescent cancer. Data from these studies are complex, contradictory and often fraught with the unique psychometric issues of measuring children and adolescents, who are distinctly different from adults.

In a classic study, Koocher & O'Malley (1981) investigated survivors of childhood cancer and described uncertainty as the "Damocles Syndrome". Similar to the greek myth involving the courtier Damocles who attended a feast where he sat beneath a sword suspended by a single thread, survivors were never free from worrying about their health. Anxieties, fears, preoccupation with bodily function, and obsessive-concern about the progression of disease are symptomatic of this syndrome. Uncertainty has been recognized as the greatest psychosocial stressor to individuals and families faced with cancer and a significant concern to adolescents with cancer (Clark-Steffen, 1993; Cohen & Martinson, 1988; Halldorsdottir & Hamrin 1996; Mishel, 1988; Neville, 2000, 2005). Mishel developed a theory of uncertainty in illness, which explores how individuals process and obtain meaning from illness related events. When uncertainty is appraised as a danger, coping efforts are employed and if effective, adaptation occurs. According to theory, if coping efforts are not effective, maladaptation or difficulty in adaptation manifests as psychological distress, family adjustment problems or poor psychosocial adjustment. Direct correlations between psychological distress and uncertainty have been reported in numerous oncology populations internationally, including adolescents with cancer (Neville, 1998).

While much research has presented the perception of uncertainty as negative, if uncertainty continues long term as in chronic illness, individuals may develop a tolerance for uncertainty. This tolerance then shifts an individual from one perspective of life to a new higher order. This may be witnessed as a reevaluation of what is seen as important in life, and an appreciation of the fragility and impermanence of life among cancer survivors (Mishel, 1990). Among young adult survivors of teenage cancer, in depth interviews revealed that survivors described themselves as possessing "a maturity beyond their years", a heightened appreciation of being alive, and intense affiliation with family and loved ones (Neville, 2000).

Resilience has emerged as a concept of inquiry important to psychosocial researchers in adolescent oncology. Haase (1997) defines

resilience as “the process of identifying or developing resources and strengths to flexibly manage stressors to gain a positive outcome, a sense of confidence, mastery and self-esteem (p. 20). Recently, Spinetta (2005) posed the question, “Can having had cancer in one’s teenage years actually be helpful rather than harmful for growth into adulthood (p. 179)?” Despite the numerous hardships and difficulties experienced in cancer, if one has supportive others, research has identified that many adolescent survivors articulate the ability to overcome adversity and having adjusted positively to their cancer experience.

A major methodological and developmental issue in studying adolescent responses to cancer lies in their ability to use adaptive denial and to manifest psychological distress differently than adults. While many measures have historically tapped psychopathological states, distress in this age group may be witnessed through school phobias, control issues, separation anxiety and somatic complaints (Rait & Holland, 1986). Furthermore, Koocher & O’Malley identified that children reacted to the stress of cancer in three ways: high anxiety and other psychological problems as a result of being preoccupied with recurrence; others believed they were now immune to cancer, and others developed an approach of not thinking about it. Not thinking about one’s cancer or the belief that one is immune to cancer has been recognized as adaptive denial, which is defined as a strategy that calls for a positive, optimistic outlook in which an individual fills his/her mind with daily thoughts and concerns rather than worries about their illness (Weekes, 1989, p.196).

The impact of cancer on adolescent development and subsequent individual progression of later developmental tasks warrants further investigation. Hinds (2000) posed the question, “do adolescents with cancer experience more or less time within a given developmental stage than their well peers” (p.VII). As a result of the cancer experience, survivors experience profound loss: isolation, altered body image, the valuable lost time of carefree adolescence where emancipation, peer relations, intimacy, and identity represent key developmental tasks to be attained. Developmental tasks among cancer survivors have been found to be

altered; some achieved faster, some slower, but many survivors describe the long term effect of cancer as needing to catch up to achieve these important adolescent developmental tasks (Neville, 2000). For instance, many survivors of teenage cancer describe a focused career path after treatment, and yet describe remaining difficulties in socialization years after treatment. As a result of being stigmatized and isolated from cancer, survivors described the long-term effect of still striving for intimacy, and the establishment of significant peer and social relationships as young-middle adults.

In recent years, interest in the psychological sequelae of the cancer survivors’ experience and its association with Post-traumatic Stress Distress has identified predictors of this long-term effect. Survivors’ perception of treatment intensity as well as life threat have been identified as significant predictors of PTSD, with young people believed to be the most vulnerable to PTSD (Hobbie, Stuber, & Meeske et al, 2000; Kaplan & Sadock, 1998).

In summary, the survivor of teenage cancer faces many difficulties superimposed on the challenges of a normally tumultuous adolescent life. While research has described the long-term effect of teenage cancer on young adulthood, as survivors age, further inquiry into later stages of life is warranted.

References for this article are available by contacting the NJCCR at 609-633-6552 or (njccr@doh.state.nj.us).

Late Effects of Treatment in Adult Cancer Patients

by

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Thanks to advances in early detection and effective treatment, the number of cancer survivors has increased from 3 million in 1971 to 9.8 million in 2001, and cancer survivors are living longer lives as well (CDC, 2004). However, treatment modalities often have serious side effects which may occur shortly after treatment or many years later. These include impaired heart, lung, kidney, and reproductive function; increased risk of developing second cancers; and constitutional symptoms such as fatigue and cognitive impairment. The risk of developing such effects is influenced by multiple factors including the age of the patient, type of cancer, and type of treatment received.

Patricia Ganz, M.D. discussed the late effects of surgery, chemotherapy, and radiation in detail in her presentation, "Cancer Survivorship: Pathways to Health After Treatment 2004 Conference" (see tables below)

Late Effects of Surgery

Abdominal surgery	Intestinal obstruction, short bowel syndrome
Lymphadenectomy	Lymphedema
Splenectomy	Immune dysfunction
Pelvic surgery	Impotence, incontinence

Late Effects of Chemotherapy

Renal	Cisplatin, Methotrexate, Nitrosoureas	Renal failure
Genitourinary	Cyclophosphamide	Hemorrhagic cystitis Bladder fibrosis
Bone	Steroids	Avascular necrosis
Cardiac	Anthracyclines Cyclophosphamide	Cardiomyopathy Congestive heart failure
Pulmonary	Bleomycin Methotrexate BCNU	Pulmonary fibrosis Interstitial pneumonitis
Ophthalmic	Steroids	Cataracts

	5 Fluorouracil	Tear-duct fibrosis
Central nervous system	Methotrexate	Structural changes Hemiplegia Seizures
Peripheral nervous system	Cisplatin Vinca alkaloids Paclitaxel	Peripheral neuropathies Hearing loss
Hematological	Alkylating agents Topo II inhibitors	Myelodysplasia AML
Gastrointestinal	Methotrexate BCNU	Liver dysfunction
Gonadal	Alkylating agents Procarbazine	Sterility Early menopause

Late Effects of Radiotherapy

All tissues	Second malignancies
Bone & soft tissues	Abnormal growth; atrophy, deformity, fibrosis, osteonecrosis
Dental/oral health	Poor enamel & root formation; Dry mouth
Central nervous system	Neuropsychological deficits; Structural changes; Hemorrhage
Hematological	Cytopenias; Myelodysplasia
Renal	Hypertension; renal insufficiency
Genitourinary	Bladder fibrosis; Strictures
Ophthalmologic	Cataracts; Retinopathy
Cardiovascular	Pericardial effusion; Constrictive pericarditis; Coronary artery disease
Pulmonary	Pulmonary fibrosis; Decreased lung volumes
Gastrointestinal	Malabsorption; Intestinal stricture; Liver dysfunction
Endocrine	Gonadotropin & other deficiencies Hypothyroidism; Sterility; Ovarian failure, premature menopause

Many research studies have documented neuropathy, fatigue, depression, weight gain, incontinence, impotence, and reduced sexual response as well as cognitive deficits following cancer treatment. Our care must extend beyond initial treatment. A first step is to more fully document the survivorship issues that exist, and then to identify side effects and help patients and families prevent or cope with side effects of treatment. Examples are as follows:

The risk of infertility associated with cancer treatments (surgery, chemotherapy, or radiation) is well known and should be discussed prior to treatments. Fertility-sparing options are available

for both men and women, and early referral to a reproductive endocrinology team is important to cancer patients who are at risk for infertility following treatment.

Peripheral neuropathy has been reported with the use of Platinum compounds, taxanes, vinca alkaloids, thalidomide, and bortezomib. The symptoms range from tingling and numbness of the hands and feet to loss of pain sensation, temperature, and deep tendon reflexes. No treatment is available to reverse neuropathy, but some interventions can be taken to prevent its occurrence. These include identifying and treating preexisting conditions, frequent assessment and careful monitoring, and early identification of the problem, with alterations to the treatment plan as needed.

The risk of secondary cancer after treatment for Hodgkin's disease is approximately six times greater than the risk for the general population. A higher incidence of leukemia, non-Hodgkin's lymphoma, lung cancer, breast cancer, gastric cancer, melanoma, thyroid cancer, and sarcoma of the bone and soft tissue exists among Hodgkin's disease survivors.

Chemotherapy agents most commonly associated with cardiac toxicity are anthracyclines, which may cause permanent myocardial damage and congestive heart failure. Radiation and trastuzumab, the monoclonal antibody, have also been associated with increased risk, especially when used in combination with anthracyclines.

Cognitive changes have been documented in patients with cancers of the breast and lung, as well as lymphoma and melanoma. In adults, these changes are usually related to chemotherapy dose and duration. Because such cognitive changes may be associated with co-existing conditions such as depression, fatigue, and menopause, they are often difficult to evaluate as specific, treatment-related late effects.

To address the late effects of treatment and other cancer survivorship issues, *A National Action Plan for Cancer Survivorship: Advancing Public*

Health Strategies was developed by The Centers for Disease Control and Prevention (CDC) and the Lance Armstrong Foundation (LAF). The following are examples of proposed strategies:

- Establish and disseminate clinical practice guidelines for each stage of cancer survivorship.
- Educate policy- and decision-makers about the role and value of providing long-term follow-up care, addressing quality-of-life issues and legal needs, and ensuring access to clinical trials and ancillary services for cancer survivors.

Ongoing commitment and dedication are needed to help cancer survivors in coping with the late effects of treatment.

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ANNOUNCEMENT



A Resource Book for Cancer Patients in New Jersey

has been revised by the Nursing & Psychosocial Advisory Group to the NJCCR.

Copies are now available, free of charge, by calling 609-633-6552.

CONFERENCE ANNOUNCEMENT

EMERGING TECHNOLOGIES: Changing the Face of Cancer Care

Friday, October 28, 2005
New Jersey Performing Arts Center
Newark, NJ

To register, visit: www.njccr.com



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